

A Parent's Right ————— by Rick Apicella, Esq.



Rick Apicella is an attorney and first vice president for Shearson Lehman Brothers, Inc. in New York City. He is a member of the Parents' Executive committee of the A.G. Bell Association and a member of CICI.

Rick resides in Oyster Bay, NY with his wife, Lillian, and their two children, Kerri (seven months) and Katie (six years). Katie received her cochlear implant in September 1989 at the NYU Medical Center. She attends mainstream kindergarten.

The recently aired *60 Minutes* segment about Caitlin Parton and her articulate, intelligent parents, coupled with the results of recent studies documenting the continuing progress on implanted children 18, 24 and 30 months post-implant, have shattered the bogus argument that cochlear implants "do not work." Additionally, these events have unmasked the real agenda of those opposed to the cochlear implant: the preservation and perpetuation of that segment of the deaf community which seeks to eliminate all choice for the deaf but one: American Sign Language (ASL).

What is particularly bothersome about the agenda being espoused by the National Association of the Deaf (NAD), and others who oppose the cochlear implant, is that it is being paraded about under false

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Whose Child

IS THIS?

Why? ————— by Larry Fleischer, Ph.D.



Larry Fleischer, Ph.D., has been a professor in special education at California State University, Northridge since 1972. In addition to his teaching responsibilities, in 1983, he became the coordinator of the Deaf Studies Program under the Department of Special Education.

Larry is deaf and was raised by deaf parents who taught him American Sign Language as well as French Canadian Sign Language. He attended two residential schools for the deaf--the Lexington School for the Deaf and the New York School for the Deaf, and graduated from Gallaudet University with the class of '67.

Larry and his wife, Vera, have two children: Flavia, their 20-year-old daughter, is deaf; their 19-year-old son, Flann, is hearing.

The power of science and advances in modern technology have led them to believe that a good, satisfying solution must exist to "cure" their deaf child. Their tendency to put all of their trust in science is also heightened by their unsophisticated impressions of deaf individuals as helpless and dysfunctional in society. It is my hope that, through this treatise, the reality of "deaf life" will take on a new perspective.

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Coming: Part III The Psychological Perspective

pretenses. While they state that they are concerned with the "moral and ethical" issues of implanting children, their concern is, in reality, nothing more than a transparent fiction created to mask their misplaced fear that the cochlear implant is a threat to the entire deaf community.

Proponents of this agenda justify their opposition to the cochlear implant by incredibly stating that only those deaf who use ASL should be able to determine the rights of someone else's child because they are

"Mutual deafness pales in comparison to the bonds formed by the love and strength one derives from one's family."

closer to and better able to understand a child who is deaf than the child's own parents.

The embodiment of this agenda is demonstrated by their current "politically correct" position that children who are deaf "must" have role models who are deaf and, of course, only use ASL. The hearing parent is bypassed, dismissed as an insignificant factor in his own child's growth and development.

Mutual deafness pales in comparison to the bonds formed by the love and strength one derives from one's family. To blindly proclaim that cochlear implants are universally wrong for all children and that parents are either incapable or unable to make that decision for their own children demonstrates a total lack of understanding of the parent/child relationship.

As a parent of a child with a cochlear implant, I find it repugnant that there exists some nameless, faceless "community" headed by "spokespersons" who take it upon themselves to deny choices and options to someone else's child. Instead of engaging in a mindless debate as to whether children should be "treated" as either small hearing people who have lost their hearing or as small deaf adults; perhaps these children should be "treated" exactly as they are: as children.

Surely no rational, reasonable person and/or "community" can question a parent's right to decide, or play a dominant role, in such issues as their child's education, morals, ethics, values, religion, where they live, friends and so on. Why, then, is the issue of language development any different?

Where is it written that it is impossible to allow for great diversity in the deaf experience? Must all who are deaf be forced into one ideological mold that begins and ends with ASL? Quite frankly, it is an apparent contradiction in terms when one proposes to empower the deaf by eliminating all their choices and options but one.

I recently read of a 90-year-old mother who showed an article on the "so-called" success of the cochlear implant to her 70-year-old son, who had become deaf at the age of two. She wanted him to have the implant surgery. But the son, in actuality, had no interest in receiving the implant because he was enjoying a rich, full life as a deaf person.

Deaf community members can understand the power of emotion and actions taken by hearing parents of deaf children. After all, parents only want what is best for their child and to help him/her fit well within the family, community, and society at large. Our position is not to deny parents their hopes and dreams for their deaf child but to gain respect as human beings so that they can succeed in the world.

It is understandable that hearing parents of a deaf child(ren) would do anything to change the child's deafness in hopes that their child won't appear to be a deaf person at all, thus avoiding a feeling of stigma in the familial unit. The medical profession, through its experimentation with the cochlear implant, believes that a better solution to overcome deafness has been developed. Consequently, a hearing parent's gravitation to the idea of a cochlear implant

"Why must deaf children be encouraged and considered for implants in the first place?"

for their deaf child is a natural reaction. As a result, both parents and medical professionals become allies -- with the medical professionals providing all of the necessary emotional security for them. Regretfully, in their quest to choose what is best for the deaf child, hearing parents develop emotional identities with the medical professionals while taking steps against another group of people whose views of the

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My daughter, Katie, is deaf. But that is not all that she is, and I refuse to allow anyone to define her by limiting her solely to her deafness. Katie does not, and should not, be forced to live in an isolated deaf community. Her neighbors, relatives and classmates are all hearing. Most of her friends are hearing, and so, too, will be virtually every other person that she encounters throughout her life. Allowing her the ability to hear and speak with these people is not a minor consideration and should not be lightly discarded as an option.

Katie's hearing loss does, without the benefit of a cochlear implant or other assistive devices, render her incapable of communicating with virtually everyone.

The absence of sound, the inability to hear, to speak and/or to understand the spoken word is far too important to forego simply for the misguided, ludicrous belief that deafness is merely enhancement of vision.

As parents, the decision to have a cochlear implant for Katie was by far the hardest decision of our lives. The decision to have our daughter undergo elective surgery, with all of the risks inherent therewith, was not easily made. It was a decision that we arrived at after doing our own research, meeting with adults and children who had cochlear implants, and meeting with those who opposed the cochlear implant. It was a well-informed, reasoned decision made without the benefit of being able to predict the future, and all the while with our daughter's best interests in our minds and in our hearts.

It is disheartening to constantly have that decision attacked by ideologues who have never met us or Katie. Their attacks are premised upon the same tired negative stereotypes used to describe all hearing parents of deaf children who do not opt for ASL, as well as any child with a cochlear implant. They are attacks premised upon a false set of presumptions.

Firstly, our decision to have a cochlear implant was not made shortly after Katie was deafened, nor was it made while in a state of shock, grief, or denial. Additionally, our decision was not made as a result of exaggerated promises, false statements, or the offering of false hope by the cochlear implant team. If anything, they *understated* their expectations and the

"deaf life" in question differ dramatically.

The story of Caitlin Parton, which aired on a segment of *60 Minutes* in early November 1992, clearly shows the deep involvement and advocacy of doctors, audiologists, and other related medical personnel toward cochlear implants. Deaf community members, however, take a different position. It is our opinion that medical professionals clearly have many incorrect ideas about the "deaf experience." This became evident to us when we challenged them over the benefits of cochlear implants for young, deaf

children. The information that parents were told by the medical group about the deaf community's fear of a threatened existence due to the "goodness" of a cochlear implant couldn't be further from the truth. Thus, as a result of their ignorance about the "deaf experience" and their lack of basic understanding of what works so well in the deaf community, parents are often denied proper and essential information about the deaf child.

The underlying magnitude of

their ignorance is that parents, unknown to themselves, are making ill-informed decisions about the lives and futures of their deaf children.

Considering the skyrocketing costs for medical services, American society is entitled to re-examine medical practices in order to determine if they are efficient, practical, and cost effective. It is my belief, and I have no hesitancy in making a recommendation to the FDA, that cochlear implants in young deaf children be handled with greater scrutiny by remaining at the "investigative" stage, at least for the present time. It is recognized in the deaf community that a deaf child who receives a cochlear implant still remains "deaf" in many ways. Until the device is perfected through advanced technology and is more cost effective in terms of its potential benefit for many children, not just a few, the situation becomes impractical for our American society to commit financially to cochlear implants for deaf children. So rather than weighing the potential benefits of a "non-perfected" cochlear implant, the real issue should be, "Why must deaf children be encouraged and considered for implants in the first place?"

Turning back to Apicella's essay, a large part of what he said reflects his ignorant views of deaf



Caitlin Parton with Ed Bradley.

results Katie would achieve. Further, when we made our decision, we were aware of the existence of the deaf community.

As with most hearing parents, we suffered from the common and prevalent misconception that all who were deaf used sign language. It was only after Katie became deaf that we learned for the first time of the existence of the auditory/oral deaf community and that there were deaf people who did speak and who relied upon spoken language as their primary mode of communication. Finally, our decision was not a choice between the cochlear implant and ASL; instead, our decision came long after our initial decision to pursue the auditory/oral path.

Katie was born hearing into a hearing family which places great importance upon the family and the relationship it fosters, develops and engenders.

*"Language development,
like time, waits for no one."*

When Katie lost her hearing prelingually at the age of ten months from meningitis, we decided to pursue an auditory/oral approach for her language development. This decision was based upon many factors and considerations, not the least of which were the importance that we placed upon familial relationships and the stark reality that we all live in hearing world. To label our decision as one motivated by an inability or a conscious neglect to love or communicate with Katie evidences the depths which cochlear implant opponents will sink to promote their agenda.

When Katie was two and a half years old, we elected to have the cochlear implant for her. Of paramount importance to this decision was the undisputed fact that if Katie was to ever learn spoken English, it was imperative that she do so as early as possible. The argument that one should wait until their child is mature

people, American Sign Language (ASL), and the deaf experience in general. Yet, he spoke with much authority about his perception of false pretenses by the National Association of the Deaf (NAD). What Apicella doesn't realize is that to be a complete human being requires the ability to fully communicate with family members, relatives, friends, and others.

All deaf children, even those with cochlear implants, have the same needs for a meaningful, satisfying, and rich human existence. They must have a signed language -- American Sign Language -- to do so. Through ASL, deaf children can see everything

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enough to make that decision for himself or herself may appear sound when viewed in an academic vacuum, but it is not practical in the real world. Language development, like time, waits for no one. The earlier a parent can make that decision, the better it will be for their child. Thus, it is not only the right, but the obligation, of the parent to act, to make a reasoned and well informed decision that is in their child's best interests. It was our opinion that the cochlear implant would expose Katie to more sounds, and thus, allow her to actively participate in mainstream society.

We have been very fortunate. More than three years after Katie's surgery, the cochlear implant has exceeded all our hopes and expectations.

Katie has progressed from a child who, even with hearing aids, could not hear sounds or speech more than a few feet away to a non-stop chatterbox who now hears the laughter of her baby sister. Today, Katie uses age-appropriate language and is in a mainstream kindergarten. She takes ballet, arts and crafts, and girl scouts. She has many friends and enjoys good relationships with her classmates and the kids in the neighborhood. She is inseparable from her best friend across the street. It is truly heartwarming to observe the relationship between Katie and her grandmother. She has developed strong, close, and loving bonds with her family.

The effect that the cochlear implant has had upon her life, and its ability to allow her to accomplish what she has, is truly immeasurable. Most importantly, she is a happy child who dispels all notions that she is incapable of living her life to the fullest.

While the past and present are certainly no guarantees of the future, they should not be discounted. Often, opponents of the cochlear implant use the inability of being able to guarantee and to predict the future as an argument against the implant. That, however, is neither a fair nor a valid argument. If being a parent has taught me anything, it is that there are no guarantees, and decisions cannot be made upon that basis.

As a parent, I would never be so presumptuous as to mandate my beliefs or my decision upon other parents. The decision whether to consider a cochlear implant for one's child is a truly personal one that is obviously based upon many considerations. That decision was hard enough to make for my child, let alone to make for someone else's child.

The issue is not whether that decision is right or wrong, for who knows their child better than his or

being said to them and, thus, can become nurtured and involved in their environment. Without ASL, they will constantly struggle to be involved in the communication exchange and will never see themselves as full human beings.

In the broadest sense, a human being, hearing or deaf, is better off having rich, meaningful, and satisfying dialogues with only 100 individuals than to have superficial, parrot like, and stifled dialogues with 10 million individuals.

A deaf child who has received a cochlear implant or is discouraged from learning a signed language is often led to believe in the simplistic idea that he/she can function well in society without a signed language. This belief is very disabling to the deaf child, even with much love and attention from the family. Without a signed language, a deaf child is far more isolated in his/her own home than in the deaf community, where the deaf child is looked upon and accepted as a human being first and foremost.

"...any attempt to force spoken English (and not ASL) as the primary language for deaf children in America is frivolous, unnecessary, and totally lacking of any human decency!"

Apicella's obsession on "the absence of sound, the inability to hear and/or to understand the spoken word is far too important to forego" prevents him from understanding further how language, ASL, can enrich the development of the deaf child. His views appear to be tilted to one side -- that there is no way for language acquisition/development other than through a spoken language.

Deaf children *must* have a signed language just as much as hearing children must have a spoken language. In America, English and ASL serve the same purpose for hearing and deaf children respectively. Hearing students are expected to refine their ability to read, write, and speak English continually throughout their K-12 education. In a similar vein, deaf students deserve every opportunity to develop their language to the highest form. This approach doesn't imply that deaf learners should shun English altogether. In fact, deaf students are exposed to English on a daily basis and are encouraged to try their best to master English as a second language to their highest level of competence. Likewise, hearing students should be given the change to learn ASL as a second language.

By learning ASL, parents not only become enriched through their relationship with their deaf

her parents, and who among us can predict the future? The issue is one of choice and options versus upon what basis cochlear implant opponents assume the right to deny those choices and options to someone else's child.

As a parent, I made the decision for the benefit of one person, and one person only -- my daughter. That decision, however, cannot, and should not, be interpreted as a blanket endorsement of cochlear implants for all children. I do not advocate such an endorsement and even if I did, it is immaterial, as I do not see what right I have to determine the rights and options for someone else's child. Accordingly, however, while I do not endorse the cochlear implant for all, I do support wholeheartedly the right of a parent to make that decision. That is what separates me and most parents from the opponents of the cochlear implant: We seek to give everyone the freedom to choose, while they seek to deny that basic right to all, regardless of the circumstances.

Before one seeks to forever deny children the option to have a cochlear implant, one had better be prepared, not only to argue but to prove without exception, that cochlear implants do not work, that no child under any circumstance can benefit from it, and that parents are always less qualified than the deaf community to decide issues that affect the lives, the interests and the well-being of their children. If cochlear implant opponents are incapable of making such a guarantee, and they are, then their argument lacks all validity. To pursue their self-serving agenda, therefore, will result in a grave injustice -- if but one child is denied the choice and option of a cochlear implant.

The argument that cochlear implants do not work ignores the living demonstrative proof of my daughter or of Caitlin Parton or countless implanted children who have been given, not denied, the chance to live and flourish in both the hearing and deaf worlds and who are living, irrefutable proof that cochlear implants do work.



"Why must deaf children be encouraged and considered for implants?"
— L. Fleischer —

children but the deaf community as well. The point is, however, that any attempt to force spoken English (and not ASL) as the primary language for deaf children in America is frivolous, unnecessary, and totally lacking of any human decency!

A mother recently called my office and asked me for some advice regarding her 25-year-old deaf son who wanders aimlessly throughout the house. When I inquired about his education and socialization, the mother explained to me that he was reared in a strict oral environment. It is very clear to me that his "oral" background has gotten him nowhere today -- poor communication skills, no job skills, no social skills. Now the mother, out of pure frustration, wants her son out of the house and involved in the deaf community. She does not realize that the "oral" educational system failed her son a long time ago.

It is unavoidable that, despite the fact that this deaf person is a by-product of "hearing values," when the general public sees him in the community, they will formulate the impression that all deaf people are sad and unproductive people.

We will continue to see another victimized group in the near future -- deaf people with cochlear implants. For this reason, the deaf community must speak out to stop the vicious cycle of negative images projected on deaf people. Unfortunately for Rick Apicella, until he realizes that "some nameless, faceless community" really understands this issue better than he, his way of thinking will never change, and his way of dealing with Katie will remain emotionally blinded as a result of his own value system.

Despite "breakthroughs" in modern medicine, many hearing parents still wish, dream, and hope for an absolute cure for their deaf child(ren). In the meantime, the deaf child(ren) are becoming emotionally wrecked by their parent's fantasized thoughts that once their deaf child has the proper training or gets some of his/her hearing back, everything will fall into place.

Members of the deaf community know that, historically in many cases, decisions made by hearing parents on behalf of their deaf child are ill-informed, ill-prepared, ill-advised, ill-founded, and ill-fated. Somehow, the idea must be conveyed that human rights for deaf children, based on the wealth of the deaf experience, must supersede the notion of birthrights for deaf children born to hearing parents.

Part III...LISTEN TO THE CHILDREN

Two psychologists, Dr. Barbara Brauer and Dr. Julia Steck, will look closely at cochlear implants in children. Deaf children will also be expressing their opinions on cochlear implants.

Coming in your June/July issue of *hearing health*.